PATHWAYS TO EVALUATION OF COMMUNITY-BASED PROGRAMS

Guidance from the CENTERED* Project's Blue Ribbon Advisory Panel

*Community-based Evaluation Networks Targeting Elimination of Racial and Ethnic Disparities

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PREFACE

BACKGROUND

In 1998, President Clinton committed the nation to the elimination of racial and ethnic health disparities in six areas: infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV infection/AIDS, and childhood and adult immunizations. If this goal is to be achieved by the year 2010 it will require concerted and sustained efforts funded by federal, state, and local governments, to candidly address the underlying causes of racial/ethnic inequities, including the disproportionate occurrence of disease, in communities across America.

The United States Department of Health and Human Services is providing leadership in this initiative and a multi-pronged approach is being taken. Included are efforts to increase research into access to quality healthcare services, social determinants (including poverty and environmental factors) of health, and the effectiveness of community-based public health programs.

There are many community oriented health promotion programs that seek to improve health among racial and ethnic communities to reduce the chronic disparities in health within these communities. The purpose of the investigator-initiated Special Interest Project (SIP25PR, 1999; aka the CENTERED Project) was to create a forum for bringing together those with perspectives that are rarely brought to the table to consider how to evaluate community-based efforts to eliminate health disparities. The result was the formation of a twenty-five member core advisory panel comprised of community leaders, scholars and evaluation professionals from around the country to guide the work of the Project. The guidance of this national Blue Ribbon Panel was then complemented by periodic involvement of ad hoc advisors to enable additional perspectives. Pathways was produced early in the project to share those viewpoints represented within the project.

Given that the context in which community-based public health initiatives take place includes diverse cultural, social and political dynamics, it is clear that an individual's health is not only the result of personal actions and behavioral choices, but also the result of environmental/economic, genetic, and socio-cultural factors over which the person has little or no control. Moreover, the well documented historical patterns of racism and societal discrimination on the part of dominant cultures since the founding of the United States have created powerful impediments to the education, gainful employment, and acquisition of wealth by non-dominant persons. These socially-accepted impediments have created obstacles that limit potential and enhance the probability of disparate outcomes in many fields, including health. Attempts to eliminate racial and ethnic disparities in health must be sensitive to these contextual issues and concurrently address those factors that contribute to health disparities if whatever gains may be made as a result of the national initiative are to be sustainable.

Truly community-based approaches to disparities elimination empower communities to actively participate in identifying factors that contribute to the existence of those disparities. Participatory processes are the key to meaningful empowerment, but they must include a valuing of community interests if those interests are to be incorporated into process outputs and into policy revisions and assurance monitoring. <u>Pathways</u> documents early guidance from CENTERED's Blue Ribbon Panel advisory group, and provides the rationale for why tailored program planning and evaluation processes are essential. The valuing of participatory processes is also a central theme of the <u>CENTERED Evaluation Guide</u>, as is the need for communities to holistically address racial equity.

Community-based public health programs operate within their own social and political context. The success or failure of a given program depends on its ability to mobilize support from both inside and outside the community. Programs need to establish credibility and trust with local partners and intended beneficiaries, while at the same time satisfying the expectations of external funders. For community-based evaluation to work, the stakeholders and evaluators must work in true partnership.

<u>Pathways to Evaluation of Community-based Programs</u> is intended to help community-based organizations (CBOs) that are running public health programs to find their own paths to the truth regarding the effectiveness of their programs. CBOs need feedback that fairly describes the results of their efforts; and, they need to know what is working and what is not.

There are many ways to gather the information needed for assessing program effectiveness, but it is critical that active involvement of community stakeholders is assured at all stages of the program planning and evaluation. This enhances the likelihood that the evaluation will produce the fair and practical recommendations needed for improving program effectiveness and assuring that community interests are valued and continue to drive the program.

METHODS

The CENTERED Project is led by the South Carolina Department of Health and Environmental Control's Bureau of Epidemiology in collaboration with the University of South Carolina Arnold School of Public Health's Prevention Research Center. The project is funded by the Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Adult and Community Health. The Project was initiated in the fall of 1999 as an investigator initiated project that was proposed for 3-years extendable to 6-years, to develop evaluation support for community-based organizations targeting to elimination of racial and ethnic disparities in health. The three project goals were:

- To establish a national Blue Ribbon Panel to guide the work.
- To develop a framework for use in building evaluation capacity for community-

- based efforts targeting elimination of racial and ethnic disparities in health.
- To develop networks of support for the evaluation of such community-based efforts.

The national Blue Ribbon Panel (BRP) was developed by an open call for persons interested in serving on such a panel. The candidates had to have significant experience in the evaluation of community-based programs and be willing to commit themselves for the duration of the project. The BRP selection process involved a committee of experts convened to review and make recommendations regarding those candidates the committee felt to be most appropriate for the BRP. The committees' recommendations were then used as the basis for inviting BRP participation. Twenty persons were invited. Five seats on the BRP were reserved to enable the BRP to expand its membership as they deemed appropriate.

During the course of the Project the BRP grew to include twenty-five highly diverse and respected members drawn from across the nation. Each has designed or conducted evaluation of community-based programs related to one or more of the following priority health areas: HIV, diabetes, infant mortality, breast/cervical cancer screening, child/adult immunization, or cardiovascular disease. Panelists have practical experience from working in communities on community-based prevention programs, and have achieved varying degrees of national recognition for their expertise in evaluating community-based public health programs.

The guidance from the BRP has been augmented through inclusion of highly experienced community-based organization leaders, public health professionals, and academics as ad hoc consultants and advisors. To add local perspectives, leaders of local community-based organizations were invited to share their experiences and recommendations during the quarterly CENTERED meetings that were purposefully held in various regions of the nation.

During the first year, CENTERED convened the Blue Ribbon Panel four times in different venues: North Carolina, Florida, New Mexico and Washington state. The variety of meeting locations enabled investigators and panel members to come together with selected advisors, CDC officials, and local community-based organization leaders to consider how best to support evaluation of community-based efforts to eliminate racial and ethnic health disparities. After numerous discussions, consensus was reached that the initial goal of developing a "generic evaluation protocol" was not consistent with the intent to incorporate into an evaluation methodology the flexibility required to be sensitive to, and respectful of core community values which influence community approaches to problem identification and resolution. During the second and third years, CENTERED reconvened the BRP an additional 6 times in venues in Texas, Georgia, California, North Carolina, and Alabama. The final meeting was held in April 2003 at the Birmingham Civil Rights Institute in Birmingham, Alabama.

Valuation of the role of community cultural beliefs during all phases of efforts to address health disparities was agreed to be essential to the sustainable success of community-based public health interventions. Therefore, it was agreed that a more appropriate project output than a rigid evaluation protocol would be sought. Instead of a single, fixed format evaluation document, it was felt that the project's output would be more useful if it consisted instead of a set of outputs

which enable those who would evaluate community-based public health interventions to be sensitized to the importance of local cultural values, and to how these influence individual and collective thinking and decision making.

That local decisions and responses to similar problems have varied significantly is clear. The variability of responses has been the result of varying local values. This is seen in the variations in governance structures, and in the variance in societal responses to voting rights, women's rights, the right to carry a gun, the terms of marriage and divorce, and the freedom of, and limits upon, self-expression.

It was agreed that instead of a single approach to evaluation, the project would produce a guide that would be tailored to enable alternative, culturally appropriate "pathways to evaluation". The project has aspired to provide a framework for evaluation which respects and builds upon both the Center for Disease Control's *Framework for Program Evaluation in Public Health* (MMWR Supplement No. 48; September 17, 1999), and the Centers for the Advancement of Community Based Public Health's (Durham, NC) refined version of that document, *An Evaluation Framework for Community Health Programs* (July, 2000) – produced with supplemental funding from CDC for the CENTERED Project.

The CENTERED Project outputs provide examples of how community and cultural values influence community approaches to problem identification; how intervention strategies used to address those problems can vary between communities; and, how community definitions of acceptable outcomes can differ from traditional public health indicators. This appreciation is essential, as evaluation instruments and assessment tools must first be calibrated to local community and cultural values for their outputs to be meaningful and useful for guiding intervention refinements of local community-based interventions.

This tailored, non-traditional evaluation approach is the consensus product of the wonderfully diverse perspectives offered by the variety of project participant – investigators, BRP members, and the broad array of ad hoc consultants, advisors, and interested others. Their invaluable contributions, their willingness to join in this challenging endeavor, and their perseverance through the challenges brought on by the dramatic shifts in national priority that occurred following the change in national administration and the events of September 11th, 2001 were critical to this project. It is hoped that the CENTERED outputs are found to be practically useful, yet scientifically sound, and of assistance for enhancing the capacity of community-based organizations to fairly and credibly evaluate their efforts to eliminate racial and ethnic disparities in health.

Thank you, Marshall Kreuter, for your shared vision and support without which there would not have been a CENTERED Project.

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